Misconceptions associated with children living with albinism: Evidence from Gutu District, Zimbabwe

Abstract

Misconceptions surrounding the genetic condition of albinism persist in many parts of sub-Saharan Africa, including Zimbabwe. Studies on albinism have been carried out in different contexts around the globe, but little is known so far about the effects of the misconceptions of albinism in the rural communities of Zimbabwe. This study examines the effects of the misconceptions of albinism in the Gutu District of Zimbabwe. Twenty-five participants were interviewed, namely care-givers and children living with albinism in Gutu District. In-depth interviews were used to gather data concerning their experiences of the misconceptions associated with albinism, the ways these misconceptions have affected them and the ways in which they attempt to mitigate these effects. Results of the study show that, although there are initiatives and programmes advocated by various stakeholders for children living with albinism, the misconceptions are still escalating. Furthermore, the study reveals stigma and discrimination as the major effects of the misconceptions in the lives of children living with albinism. In conclusion, the study recommends the establishment of a community-based protection model for people living with albinism, which integrates all stakeholders involved in mitigating the challenges that emerge from the misconceptions of albinism in Zimbabwe.

Keywords: stigma, albinism, protection, misconceptions, Zimbabwe

Introduction

Albinism is a medical condition that arises from a recessive genetic mutation that causes the deficiency or absence of pigment known as melanin (Baker and Lund, 2009). Lund (2014) and McLeod (2010) theorised that albinism was derived from the Latin word '*albus*' meaning 'white' and hence the term '*albino*' emerged in the 17th century. Albinism as a term was coined by Portuguese explorers to describe a group of 'white Negroids' on the west coast of Africa. McLeod further argued that albinism has provoked much thought and speculation among many people. Individuals with albinism, who appear to be a strange and separate race, have fascinated explorers and missionaries for centuries (Lund, 2014). MacLeod (2010) argued that people with albinism were used in the 18th and 19th century debate as proof or counterproofs for arguments concerning the origin of humanity and the variety of complexions among people.

These speculations about albinism do not however correspond to the facts of albinism. Albinism is a genetic condition that is passed on from parents to children. Many people are carriers of the recessive gene that results in giving birth to a child with albinism. It is not a curse. In this regard, such myths and misconceptions of albinism have led to discrimination and stigma, which in turn spur abuse and violations against the rights of persons with albinism. Tigere (2016) and Pollock (2010) asserted that discrimination infringes on the fundamental rights and basic freedoms of human beings. Children living with albinism are violated from social, economic and political freedoms. Explicitly, the Human Rights Council (2013,6) revealed the various forms of discrimination and abuse of persons with albinism to include social stigma and derogatory name calling, gender-based sexual violence, killings and harvesting of body parts, a lack of appropriate medical attention, and discrimination from employment and education. Thus, the challenges faced by children with albinism in Zimbabwe are premised in both structural and direct violence (Public Health Project Africa, 2012; Galtung, 1999). It is based on the forgoing that this study sought to examine the misconceptions of albinism in Gutu District of Zimbabwe.

Although some studies, such as that conducted by Phatoli, Bila, and Ross (2015), have found that while some of the persons with albinism acceded to negative stereotypes, others coped well, despite these adversities. However, due to the persistence of the misconceptions about this condition in the rural communities of Zimbabwe, Public Health Project Africa (2012) and Machoko (2013) established that the protection of people living with albinism was being gradually eroded. In Southern Africa and Zimbabwe, these misconceptions include the idea that sexual intimacy with a person living with albinism will cure HIV infection or AIDS and an idea that albinism is a result of witchcraft. The beliefs that albinism is a curse from God or ancestral spirits and that people living with albinism are not human beings, but unfinished creatures, have a profound impact on the socio-economic lives of people with albinism. Baker, Lund, Taylor, and Nyathi (2010) argued that these misconceptions affect family life and interfere with access to education, employment and marriage. Albinism is more noticeable among black people than white people, perhaps resulting in more stigma in African communities.

Whilst there are studies on albinism conducted in different parts of Africa, such as by Ntinda (2008), Phatoli et.al (2015) and Dapi, Tambe & Monebenimp (2018), little phenomenological research has been carried out within the Zimbabwean rural communities. Focusing on the Gutu District of Zimbabwe, therefore, this study sought to examine the misconceptions associated with albinism, how these misconceptions affect people with albinism and how they cope with the adversities, problems and traumatic situation caused by these effects. The views of both children living with albinism and their care-givers were sought. This article begins by describing the context of the study and the effects of the misconceptions of albinism. Subsequently, the research methodology, data collection methods and analysis are presented. The findings are presented and discussed, and finally the implications for social work practice in the Gutu District of Zimbabwe are presented, with attention to a proposal for a community-based protection model of children living with albinism.

Albinism globally and in the research context

According to Thuku (2011,2), the exact prevalence of albinism among humans is not clear, but estimates say that the ratio is about 1 in 17,000 people. Lund (2014 :642) indicated that among 1.3 million schoolchildren in Zimbabwe, a total number of 278 are living with oculocutaneous albinism, giving a prevalence of 1 in 4,728.

Misconceptions surrounding the genetic condition of albinism persist in many parts of sub-Saharan Africa. Whilst albinism is a global challenge, according to the United Nations (2013), its stigma is more pronounced in African black pigmentation than in the white populace. In Zimbabwe, people living with albinism are less than in other countries such as Tanzania, Burundi and Nigeria where violence against people living with albinism has been highly experienced, according to the WHO (2017) and Dapi et.al (2018). The distribution of people living with albinism is more highly concentrated in the urban areas than in the rural communities of Zimbabwe (Lund, 2014). However, the survey carried out by Lund (2014) and the WHO (2017) convergently showed that the impact of albinism is more noticeable in the rural communities than in urban areas because of various socio-economic factors, such as poverty and cultural and religious beliefs. There is a growing evidence of discrimination and stigmatisation faced by people living with albinism in Zimbabwe.

Choruma (2007) posited that the Zimbabwe Albinos' Association (ZIMAS) has been involved in advocating and lobbying through albinos' awareness programmes, mobilising support in cash or kind from the communities, government and non-governmental organisations since its

inception in 1997. She further emphasised that although much was expected out of the ZIMAS' effort, the community and government support of the programme was not convincingly satisfactory. However, despite the little support they received from various organisations and the government, ZIMAS managed to plead with some individual government senior authorities and could acquire Assistance Medical Treatment Order (AMTOS) in 2000 (Choruma, 2007). ZIMAS also participated in child participatory activities and some national events such as African child and disability advocacy. According to the Ministry of Health and Child Welfare (MHCW) (2010), these events were meant to collectively empower and foster capacity building towards the achievement of a sustainable livelihood for children living both with and without albinism. Notwithstanding the effort by ZIMAS, Machoko (2013) lamented that there was little attention from the government through policing to see to it that people living with albinism, as a special group, found support. Instead, misconceptions continued to ruin their livelihood and freedom to access other utilities of life as normal human beings within societies.

According to Baker (2012), albinism is subjected to a plethora of challenges that interferes with the socio-economic and livelihood development. Baker argued that traditional beliefs relating to the conception of a child with albinism as punishment for misdemeanour and the notion of the intermediary position of the people living with albinism between the real world and the spirit world, run alongside the stereotypes of albinism, which include a fear that albinism is contagious and the belief that people with this condition are mentally handicapped. Chinenye and Odigie (2010) revealed that in recent years, a new set of beliefs had emerged, generated in response to the current issues in sub-Saharan Africa. The belief that sex with people with albinism is a cure for HIV/AIDS is one of the most disturbing. In the same vein, Cimpric (2010) highlighted the sale of body parts, specifically genitalia, from people with albinism. Malone (2009) indicated that in Tanzania and Burundi, people living with albinism are hunted like animals and killed for different reasons, such as harvesting of body parts for ritual purposes. Furthermore, Nitnda (2008) added that people living with albinism are believed to have a short life span and don't die, but simply vanish.

Methodology

This was a phenomenological study located in a qualitative paradigm (Merriam, 2009). The argument for qualitative methods, according to Creswell and Miller (2003), is that they are best suited to the study of the meaning and purpose of human action because knowledge claims are derived. As such, this study deployed a phenomenological study within a qualitative research tradition to examine the misconceptions associated with children living with albinism in the local rural communities of Gutu District of Zimbabwe. Hewlet (2013,74) remarked that a "qualitative approach allows for the collection and analysis of the naturalistic data to be understood in relation to a particular social context and setting". Thus, through the phenomenological qualitative paradigm, this study conceptualised the complex experiences that the care-givers and children living with albinism encounter in Gutu District of Zimbabwe.

Two populations were identified: children living with albinism and their care-givers. Purposive sampling was used to sample each population. The sampling criteria for the population of children living with albinism were that they were between the ages of 10 to 17, living in the Gutu District of Zimbabwe for a period of not less than five years. The rationale for choosing children between the age of 10 and 17 was that they were old enough to assent to their participation in the study, in addition to the proxy consent from their care-givers. The sample included one 18-year-old youth living with albinism who was head of a child-headed household. The timeframe of living in Gutu District for at least five years was selected on the basis that it is long enough for an individual person to adequately grasp the phenomenological

experiences of people living with albinism (Bloor, Frankland, Thomas and Robson, 2001). The criteria for sampling care-givers was that they had to be the biological parents, grandparents, brothers, aunts or a close family relative of a child living with albinism in the Gutu District. In total, 10 children living with albinism and 15 care-givers were sampled through a snowballing method, whereby the researcher was referred to subsequent participants by earlier participants.

Data were collected through in-depth individual interviews. Questions included:
"In your understanding, what is albinism?"
"What are the misconceptions and challenges associated with albinism?"
"What coping strategies are you using to survive despite the prevailing misconceptions?"
"Why are the misconceptions persisting despite the efforts put to mitigate them?"

Logistically, the data collection process proved difficult because the children living with albinism did not live in one area but stayed far away from each other. Data were collected in the local indigenous language, namely Shona, and then translated into English by linguistic experts for accuracy and then transcribed for analysis.

The data were analysed using the model of thematic analysis suggested by Braun and Clarke (2006), who argued that thematic analysis provides an accessible and theoretically open-coding approach to analysing qualitative data. This involved the researcher having to familiarize himself with the data, and then reviewing and defining the themes. The trustworthiness (Lincoln & Guba, 1985) of the study was enhanced by triangulation of sites and sources, using purposive sampling and providing a detailed description of the methods used.

Since the study involved human participants, pertinent ethical issues were considered prior to and during the study. Ethical approval from the relevant ethical department, namely the Research Council of Zimbabwe (RCZ), was obtained before the study commenced. Written informed consent for care-givers, and assent and proxy consent for children under the age of 18 was obtained. Questions in the study tools were focused on the subject and as far as possible, nothing outside the scope of the study was discussed.

Findings

Children's views on the discontent between medical and cultural views on albinism

Most of the children living with albinism showed that they were ignorant of their condition. Whilst they confirmed that they sporadically meet practitioners who tried to educate them on the truth of their condition, they were affected more by the misconceptions than the truth about their condition. When asked what albinism is, one of the school going children remarked:

> *"I have come to believe that I am cursed by God, because I don't have friends at school and at home. Some people directly told me that albinism is contagious, and they don't want to share anything with me. If it was not a curse, I was not going to be treated that way."*

In support of this view, another child who was no longer attending school, citing stigma and discrimination from both teachers and fellow students, said:

> *"Honestly, our condition is hell on earth. I tried to endure going to school, but I was told by one of the students that her mother told her that albinos are animals and we don't die but we simply disappear. In the classroom, some fellow students were not*

willing to share textbooks with me. This embarrassed me, and I thought of quitting school and staying at home."

Similarly, one of the child living with albinism also narrated how he dropped out of school because of stigma and discrimination from both teachers and students. He indicated that they would call him derogatory names and he suffered discrimination from social activities such as sports and recreational undertakings. In this regard, when asked about his perception on his condition, he remarked:

> *"As we speak now, I am not at school, not because I don't want to go to school, but the level of discrimination and stigma associated with our condition at school is serious. If it was only coming from other children, while our teachers accept our condition, it was better."*

Mostly, the findings from the children living with albinism confirmed that their condition could not merely be a genetically inherited condition, but rather as a result of a curse from God or ancestors or an act of witchcraft. This was corroborated by another child who remarked: *"My condition is not normal, I think my parents told me that I was bewitched while in my mother's womb"*.

One of the 18-year-old child-headed care-givers living with albinism, who had just completed his ordinary level studies, confirmed that he could not get any employment, despite being qualified, because of his condition. He miserably narrated his ordeal that he lived with his grandmother and thought that if he could find employment he would be able to take care of his old aged grandmother, but it was to no avail. He said:

> *"No matter how much people may try to convince me that my condition is the same with others, it is not. I have come to conclude that HIV/AIDS is better than albinism because people living with HIV/AIDS are employable than a person living with albinism. I applied for a place to go to college and I am always getting regrets."*

Another girl living with albinism even went to the extent of doubting if she would marry because of her condition. On this note, she said:

> *"I am turning 18 years this year and I have never been approached for dating with anyone. This causes me to wonder if I would get married one day. I think men do not want women living with albinism because of all those stereotypes leveled on us."*

One of the children living with albinism pointed out that because of the misconceptions associated with albinism, her mother was a single-mother. She remarked that her father and mother separated because she was born with albinism and her mother was accused of infidelity and practising witchcraft. In her words she said:

> *"The misconceptions and stereotypes about our condition seems to be more acceptable than the truth. I am being taken care of by a single mother because she was divorced because I was born with albinism and all sorts of misconceptions were blamed on her until she was ordered to leave her matrimonial home."*

Finally, some children living with albinism confirmed that both at school and in the communities, they were not called by their names like other children. Instead, they were called

derogatory names or nicknames that stigmatised and discriminated against them from others. One of the children remarked:

> *"I am not sure if at school they really know my name. They just call me with the nicknames of my pigmentation. Some call me a 'wild white person' while others call me 'mungawu'* [white person]. *This really disturbs me."*

Whilst other children living with albinism indicated that the community stigmatized and discriminated against them out of ignorance, others confirmed that some did it deliberately. Children living with albinism confirmed that the government and its arms did very little to support them in both cash or kind. The laws of the country are too loose to protect them from being abused and discriminated against by teachers and other fellow students at school. Hence, most of them are dropping out of school because they lack financial and material support.

Children's views on the deficit of protection strategies for children living with albinism

Children living with albinism confirmed that as far as they are aware, no operational measures have been put in place by the government or their communities to mitigate the escalation of the effects of the misconception associated with albinism. Most of them indicated that in Gutu District they know of Batanai HIV/AIDS support groups, to which their parents took them for gardening. However, whilst they appreciated some form of empowerment from Batanai, ~~but~~ they indicated that it was not doing enough to de-escalate the level of stigma and discrimination they suffered from the community because of albinism. One of the participants said:

> *"To tell you the truth, as people living with albinism, I don't know of any specific measure from the government that seeks to directly exonerate us from the effects of the misconceptions of our condition such as stigma and discrimination. Maybe in the urban areas or other rural communities where I have never been, but not here in Gutu District."*

In support of this view, another child remarked:

> *"Batanai HIV/AIDS support group is doing its best to help people affected and infected with HIV/AIDS and not people living with albinism. People living with HIV/AIDS look happier than us, because the whole world is fighting against AIDS, which is not the case of our condition."*

Another child was quoted as saying:

> *"At school, we only see organizations that come to teach people about the misconceptions about HIV/AIDS and not even a single day have we seen organisations that talk about the misconceptions of albinism. Yet at school that's where we experience a lot of stigma and discrimination."*

When asked what they thought should be done to exonerate them from the challenges of stigma and discrimination caused by the misconceptions of their condition, most of the children indicated the need for establishing relevant support that specifically targeted people living with albinism. One of the children said, *"We need support groups that specifically target people living with albinism, like the AIDS service support groups"*.

Some children pointed out that the government must intervene with its laws and policies to punish the perpetrators of any violence associated with the misconceptions of albinism. One of

the child had these words to say: *"I think if the government really wants to protect us, it should enact laws to punish whoever calls us with derogatory names and other forms of violence like sexual advancement for HIV/AIDS cure and luck medicine"*. Other children pointed to the increase of advocacy and learning programmes on the misconceptions of albinism, not only for people living with albinism, but the whole community.

Care-givers' views on the discontent between medical and cultural views on albinism

The most prominent view from the care-givers indicated that they knew the condition of albinism from a medical point of view as it was explained to them by the medical practitioners. However, their understanding and their practical experiences in their communities was totally different. The disjuncture between the true biological understanding of albinism and misconceptions was mentioned by most of the care-givers who participated in the study. When asked about their understanding of albinism, one of the care-givers said:

> *"Yes, the medical experts explained to me the condition of my child, but when I went home it was not understood the same way with my family members, including my husband. The family members told me that it was the work of the devil. They told me that I was bewitched. Some went even to the extent of accusing me of adultery and as a result they said I was cursed by God and ancestors. As we speak right now, my marriage is irretrievably broken, because of different views associated to the condition of my child."*

Normally, it was expected that when people had knowledge about albinism, the effects of albinism to the care-givers and children must be de-escalated. On the contrary, when the participants were probed for further clarity on why misconceptions were escalating, despite the true knowledge about the condition having been disseminated by the medical practitioners, one of the care-givers remarked:

> *"The main challenge of misconceptions of albinism is not with us as the biological parents, but our relatives, community and at school where our children mingle with their peers and other people who doesn't have the knowledge that we have about the condition of our children."*

The foregoing sentiments indicated that misconceptions of albinism caused both mental and emotional challenges to the care-givers. This was confirmed by one of the male care-givers, who said:

> *"My son is no longer going to school because of the stigma and discrimination inflicted by both fellow students and teachers on the basis his condition. Some are calling him 'Zeru Zeru' meaning 'ghost like creature', while others refer to him as 'murungu dondo' meaning 'wild white man'."*

A second prominent view from the care-givers indicated ignorance on albinism. Instead, they confirmed that albinism is a curse from God and ancestors. Whilst this view was shared by several participants, one of the participants, when asked about her perception on albinism, said:

> *"Honestly, in theory we may be forced to believe what the doctors say about albinism, but practically the challenges that our children are facing is beyond the physical but rather spiritual"*.

This view was corroborated by another participant who religiously remarked: *"I believe that albinism is a curse from God or ancestors which follows the bloodline of that lineage"*.

When probed about who might have been cursed between the child and the parents, this participant remarked:

> *"It might not be the immediate biological parents of the child living with albinism, but their forefathers might have committed an abomination that caused the whole family to be cursed in the form of albinism"*.

The participants' remarks showed that these religious and traditional misconception of albinism are deeply rooted in the rural community of Gutu District. It was evidently shown by some participants, who even proclaimed that they constantly visited the religious leaders and traditional healers for assistance, more than the hospitals, because they found faith healers to be more helpful that hospitals.

Lastly, when the care-givers were further probed about the misconceptions of albinism within their community and family circles, they pointed out that children and adult people living with albinism were sexually abused under the belief that they cure HIV and AIDS. This view was confirmed by one of the care-givers who exclaimed

> *"Although, sexual abuses of children living with albinism are not constantly reported to police but the traditional leaders in our communities are always sitting over these issues"*.

Another care-giver added:

> *"Children living with albinism are afraid of going to school because some people believe that the body parts of people living with albinism can be used for enhancing business viability. As a result, they are forced to live indoors"*.

This misconception caused a lot of psychological torture, stigma and discrimination of the children living with albinism and even their parents because they are believed to be genetically carrying that curse in them.

Care-givers' views on the deficiency of mitigatory strategies

Most of the care-givers indicated that whilst the challenges associated with albinism are difficult to mitigate, they were not just watching their children and themselves suffering from stigma and discrimination. Instead, most of the care-givers confirmed that they had joined Batanai HIV/AIDS support groups in Gutu District, not because they were suffering from HIV or AIDS, but to learn different life skills and participate in projects. When asked how they were fighting the effects of the misconceptions of albinism, one of the care-givers remarked: *"I joined Batanai HIV/AIDS support group in my area to learn life skills and do projects for a living with others"*. Joining support groups was corroborated by several other care-givers who confirmed that under the auspice of Batanai HIV/AIDS support groups they were doing gardening and learning life skills from different counselors. One of the care-givers remarked:

> *"Whilst stigma and discrimination is still there to my children living with albinism, but ever since I joined this support group, I have found my home"*.

The participants clearly pointed out that whilst Batanai HIV/AIDS support group was operating under the auspice of assisting people infected and affected with HIV or AIDS, it ended up incorporating everyone voluntarily willing to join the support groups and engage with its activities. The care-givers noted that there were no operational support groups or associations that dealt directly with albinism, but their issues were partially incorporated with some local non-governmental organisations which came once after a long time. In support of the foregoing view, one of the care-givers said:

> *"The major challenge with these non-governmental organisations, including Batanai support groups, is that they don't have funding and our meeting are ending up becoming too social and casual than helping us meeting our immediate needs."*

Another group of the care-givers reported that they had joined Zimbabwe Albinos Association (ZIMAS), but the group naturally died in the rural areas because of lack of coordination. When asked how much they were benefiting from ZIMAS, one of the care-givers indicated that the association did not have structures in the rural communities and that nothing had come from it at all. Another participant corroborated this sentiment saying,

> *"In my best knowledge, ZIMAS just registered children living with albinism in schools and in our rural community 10 years ago and they never come back to us. As I speak, we don't know whether it is still there or not. So, there is nothing comes from ZIMAS. Only promises that were never fulfilled."*

On the same note, another participant said:

> *"If the government really wanted to assist people living with albinism they would support associations like ZIMAS, because it was a relevant organization to deal with our challenges and I think it failed to fulfil its promises because of lack of resources."*

Care-givers also pointed out that they sometimes found some help from the local leadership, such as politicians, councilors and business people. One participant further indicated that the main challenge was that these good Samaritans normally gave material help which id not remove stigma and discrimination associated with misconceptions bedeviling their children. In her words she remarked:

> *"Honestly, I am not undermining the help that is being rendered to us in form of clothes, school fees and food from different organizations and even the government, but these do not reduce the stigma in our children from schools and in the communities. More so, their interventions are not well coordinated. The community needs to be educated and empowered in the true knowledge of albinism to reduce the stigma in our children."*

When asked what they thought should be done to reduce the stigma and discrimination that emanated from the misconceptions of albinism, one of the participants said:

> *"We need the government to intervene with policies that socio-economically empowers children living with albinism"*.

Another participant suggested:

> *"All the stakeholders must come together and work as a team for people living with albinism and this formation will help to disseminate the true information about albinism to the rural communities like the Gutu District of Zimbabwe."*

Discussion of the Findings

Different views of the misconceptions of albinism and their impact on the well-being of children with albinism and their care-givers have been presented. The most prominent view from the care-givers confirmed that they knew what albinism is from a medical point of view, but stigma and discrimination persisted. This finding converges with Baker (2012) and Choruma (2007), who argued that even though Africans are exposed to some contemporary understanding, they continue to espouse their culture and tradition. It is, therefore, in these cultural and traditional beliefs that these misconceptions and mythological beliefs of albinism are entrenched. In this view, Chinye and Odigie (2010) contended that culture and tradition are most vital for identity, but if not well managed, they disempower people.

Further to this, the results showed that information about albinism was not transmitted beyond the biological parents of children living with albinism and thereby making it futile to affect the community at large. Prominently, this view confirms that the children living with albinism and their care-givers continued to suffer from stigma and discrimination despite the level of knowledge accumulated about albinism. Predicated in the findings, the ignorance precipitated by cultural and traditional beliefs are fundamental ingredients of lack of a sustainable and holistic protection mechanism for children living with albinism. This finding was confirmed by the care-givers and overwhelmingly corroborated by the children living with albinism, who emphasised that their condition was a result of a curse. Children living with albinism believed beyond any doubt that they were cursed and that was the reason why there was little support from both the private and public sector.

The second prominent view in the understanding of albinism was of those who indicated that they did not believe that albinism is a genetically inherited condition but rather a curse from God and the ancestors. This cluster of participants' view concurred with Cimpric (2010), Malone (2009) and Baker et al. (2010), who convergently revealed that Africans are traditionally superstitious and religious. The results showed that most of the misconceptions associated with albinism in the rural communities are a product of their religious and superstitious beliefs. For instance, in this view, most of the care-givers subscribed to religious and mythological beliefs and views of albinism. Lund (2014) argued that the power of the misconceptions of albinism in Africans is their misplaced thinking of reality entrenched in their religious and superstitious beliefs. Whilst among the care-givers, this view was the second most prominent view, but among the children living with albinism it was the most prominent view. As a result, this view seems to have caused more damage in the lives of both care-givers and children living with albinism. The findings confirmed that some children dropped out of school and some care-givers suffered a broken marriage because of the intensity of the effects of misconceptions of albinism.

The findings showed that stigma and the discrimination of children living with albinism is a result of the absence of coordination among the different actors in the community. This view was confirmed in literature by Dapi et.al (2018) and Ntinda (2008), who argued that protection against adversity should be inculcated at individual, family and community levels. In this view, the findings concurred with the literature reviewed earlier in this article, namely that the use of appellation, demeaning and derogatory names and terms against albinism persist in our communities. The United Nations (2013) and Human Rights Council (2013) opined that this has led to discrimination based on colour, which is against the rights guaranteed in the Universal Declaration of Human Rights (UDHR) and all other international and regional human rights instruments. Based on this analysis, it is clearly shown that there is lack of a concerted community-based resilience model that inculcates understanding and resilience

mechanisms in the lives of children living with albinism and their care-givers, as well as in community members.

As mitigatory strategies, the findings in the study from both the children living with albinism and their care-givers showed that du to a lack of support, they are forced to do jobs that are possibly even hazardous to their health. Some participants mentioned that they sometimes found help from well-wishers and more especially as initiated by ZIMAS. However, because of a lack of back-up support, ZIMAS could not also afford to give much substantial support to children living with albinism except advocacy and education to the society about albinism, which did not help much to fight the stigma and stereotypes already attached to albinism. Some albinos even mentioned that instead of continuing with school, where even teachers discriminated against them because of misconceptions, as a coping strategy they found it safer to stay at home than going to school.

From a human rights point of view, and as suggested by United Nations (2013) and Phatoli et.al (2015), that every living being must have the capacity and adaptive mechanism to subdue adversity in their life situation, the findings of this study have shown that in the Gutu District there is a great need of inculcating cultural, ideological and intellectual capacity in the lives of people living with albinism and their care-givers. Instead of the community members and the actors within the community helping people living with albinism to resiliently subdue their challenges, the findings indicated that in some instances they acted as perpetrators of misconceptions in the lives of the victims. For instance, the findings revealed that there are some religious and traditional leaders who still espouse some of the misconceptions of albinism, such as that albinism is a curse and punishment from God and ancestors. Further to this evidence, the findings also showed that there is a lack of the resilience capacity that is based on consolidated effort and abilities from different actors and their social and relational environment. This idea strongly corroborates to Swanepoel (2006) who emphasised that sustainability and protection are not primarily a set of individualistic or personal processes or capabilities. They are rather something located in the transactions between people and their social environments. Thus, evidence from this study shows the need for that gap to be bridged by establishing a community-based stakeholder network and cooperation to fight the misconceptions associated with albinism.

Predicated in the forgoing discussion, it is evident that there are various critical anomalies within communities that need to be addressed through the construction of a community-based protection model for people living with albinism. Firstly, both the children living with albinism and care-givers showed that there the government is doing very little to mitigate the challenges caused by misconceptions of albinism. Secondly, whilst other participants indicated that they knew the reality of albinism, the study prominently showed that there is much ignorance about albinism in the rural communities. Thirdly, there is disharmony between the stakeholders at grassroots level that interactively advocate for the rights of children living with albinism. Fourthly, there is a lack of resources and will-power of the stakeholders to fight stigma and discrimination caused by the misconception of albinism. Figure 1 below indicates the suggested community-based protection application model for people living with albinism.

Figure 1: Community-based protection model for children living with albinism

Illustrated in Figure 1 above, the mitigation of the effects of the misconceptions of albinism, such as stigma and discrimination at grassroots level, requires an integrative stakeholders approach. These stakeholders will bring their will-power and resources together within their areas of specialty to help the community understand more about children living with albinism as other children within the community, but at the same time address their special needs. Regarding this application model, the resources and the will-power of the stakeholders are the foundation of fighting the effects of the misconceptions of albinism. This is then followed by the integration of the stakeholders within the community as pillars who sustain the well-being and protection of children living with albinism. The efforts of these stakeholders should be integrated within the areas of their specialty, such as legislative, policing, advocacy, funding, educating, caring and support resting upon the foundation of resources and will-power of the stakeholders at grassroots level within that community.

Conclusion and Implications

The evidence suggests that the impact of the misconceptions of albinism is particularly serious in the areas, such as in Gutu District of Zimbabwe, where albinism is associated with myths, legends and folklores, in turn leading to stigmatisation and discrimination. This is mainly insinuated with the absence of a community-based protection model targeting children living with albinism, their care-givers and the community at large. By implication, to reduce the escalation of the effects of the misconceptions of albinism as shown by the findings, social workers, in consortium with the relevant government bodies, must promote the human rights laws at grassroots level, as suggested by Mandaza (2012). Social workers must also ensure that there is effective implementation of the human rights laws to deal with discrimination of people living with albinism.

Whilst the United Nation's policies on disabilities have a section that exclusively recognises people living with albinism as a special group, which requires special attention from the governments and stakeholders, the findings have shown that there is a lack of such exclusive policy for people living with albinism in Zimbabwe. Instead, the people living with albinism are bundled together with people living with other forms of disabilities, which is an impediment for them to acquire special help that is commensurate with their special challenges. To address this discrepancy, social workers must advocate for the need of a policy that will recognise persons with albinism as a vulnerable group with special needs. This can be attained by an inclusion of provisions into various statutes such as the Persons with Disabilities Act and prohibition of discrimination based on genetic inheritance. Finally, social workers must host public education programmes that will educate albinos, as well as members of society, on the causes and characteristics of albinism. The findings have also shown that there is no concerted effort among various stakeholders in fighting albinism at grassroots level. As such, social workers, in consortium with other stakeholders, must establish a community-based resilience model for people living with albinism at grassroots level to abate the escalation of misconceptions of albinism. The study therefore recommends the establishment of a community-based resilience model for people living with albinism by interaction with the people and their social environment.

References

Baker, C., P. Lund, J. S., Taylor, and P. Nyathi. 2010. "Cultural and literary perspectives on the myths surrounding people with albinism in South Africa and Zimbabwe." Journal of African Cultural Studies 8 (22): 169-181.

Baker, C. 2012. Representing: "The tribe of the Ghosts": Stereotypes of Albinism emerging from reports of recent attacks in Tanzania and Burundi. Lancaster, Lancaster University

Bloor, M., J. Frankland., M. Thomas., and K. Robson. 2001. Focus Groups in Social Research. London: Sage Publishers

Braun, V., and V. Clarke. 2006. "Using thematic analysis in psychology." Qualitative Research in Psychology, 3:77-101

Choruma, T. 2007. The Forgotten Tribe: People Living with Disabilities in Zimbabwe. London: Progressio Publications

Chinenye, P., and D. Odigie. 2010. "Albino Killings in Tanzania: Implications for Security." Peace Studies Journal 3: 69-75

Creswell, W.J., and D.L. Miller. 2003. Determining Validity in Qualitative Inquiry: Theory into Practice. Ohio: Ohio State University.

Crimpric, A. 2010. "Children accused of Witchcraft: An Anthropological Study of Contemporary practices in Africa." Dakar: UNICEF. *http://www.econet/file.uploaded/1930/unicef*.

Dapi, L.N., B.A, Tembe., and F. Monebenimp. 2018. Myths surrounding albinism and struggles with albinism to achieve human rights in Younde, Cameroon. Human Rights and Social Work, 3(1), 11-12

Galtung, J. 1999. Peace by Peaceful Means: Peace and Conflict, Development and Civilization. London: Sage Publication Inc.

Gunderson, L. H., C. R. Allen., and C.S. Holling. 2010. Foundations of ecological resilience. Washington, DC: Island Press.

Hewlet L. 2013. Decontextualizing Knowledge in the curriculum in Public Management. Unpublished PhD Thesis. Johannesburg: University of Witwatersrand.

Human Rights Council. 2013. Human Rights Situations that require the Council's attention: Reports of the Independent International Commission on Albinism. Geneva: Human Rights Commission.

Lincoln, Y., and E.G. Guba. 1985. Naturalist Enquiry. Newbury Park, CA: Sage

Lund, P. M. 2014. "Distribution of oculocutaneous albinism in Zimbabwe." Journal of Medical Genetics, 33: 641-644

Luthar, S. S. 2006. "Resilience in development: A synthesis of research across five decades." Developmental psychopathology, 3(1):739–79

Macchoko, G.C. 2013. Albinism: A life of ambiguity: A Zimbabwean experience, African Identities, 11(3), 318-33

Malone, A. 2009. "The Albino Tribe Butchered to feed a gruesome trade in "magical" body parts." *http://www.daily* mail.co.uk/article-12/5949

Mandaza, I. 2012. Re-Inventing Alterity: The Woman and the Albinos in Takadini's Subtext. Harare: SAPES Publications.

McLeod. T. 2010. Albinism and the Contingencies of Stigma: London: University of Cambridge Press

Merriam, S.B. 2009. Qualitative Research: A Guide to Design and Implementation, San Francisco, Jossey-Bass-A Willy Imprint Publishers.

Ntinda, R.N. 2008. Customary practices and children with albinism in Namibia: A constitutional challenge? Children's rights in Namibia*. http://en.afrik.com/article13487.html*.

Pollock, R. 2010. Tanzania: Albino Killings Related to Ancient Tribal Beliefs. Media Global. New York: Publications

Phatoli, R., Bila, N., and E. Ross.2015. Being black in a white skin: Beliefs and stereotypes around albinism at a South African University. African Journal of Disability, 4(1), 22-43

Public Health Project. 2012. Challenges faced by People Living with Albinism in Africa Harare: Public Health Projects.

Swanepoel, F.H. 2006. Development: Breaking the cycle of poverty, Lansdowne, Junta and Co.Ltd.

Thuku, M. 2011. “Myths, Discrimination and the call for special rights for persons with albinism in Sub-Saharan Africa. Albinism Foundation of East Africa.” www.albinismfoundationea.com/.

Tigere, A. 2016. Weaving Hope for our Children: Home based Care, an entry point for enhancing psychosocial support for children affected by HIV and AIDS. Randburg: Regional Psychosocial Support Initiative (REPSSI).

World Bank. 2012. Sub-Saharan Africa: From Crisis to Sustainable Growth. Washington D.C: World Bank.

UNICEF. 2011. Caring for Carers: Managing Stress in those who care for people with HIV/AIDS. UNICEF, Geneva.